Pennsylvania Organ Donation Advisory Committee 2015 Annual Report



Message from the Organ Donation Advisory Committee Chair...

Dear Members of the General Assembly:

In 1994, the hopeful efforts of families whose loved ones had died waiting for an organ transplant were fulfilled when Governor Robert P. Casey signed the landmark legislation Act 102, making Pennsylvania the model in the United States for promoting organ and tissue donation. Much has changed in the 20+ years since the passage of Act 102, and, although the commonwealth remains a leader in many facets of the donation and transplantation process, it has not kept pace with other states in adopting provisions of the revised Uniform Anatomical Gift Act (UAGA). Developed in 2006 by the Uniform Law Commission to enhance the process of making an anatomical gift more streamlined and consistent across states, the revised UAGA embodies clinical best practices and seeks to maximize the number of organs available for donation. It has been almost universally accepted, with adoption in forty-seven states.

The great news is that the current Donate Life PA Act in the General Assembly (SB180) logically builds upon the best of Act 102 and incorporates key provisions of the revised UAGA. Importantly, the Donate Life PA Act would provide for education about organ and tissue donation in secondary schools, medical schools and nursing schools; encourage cooperation among medical examiners, coroners and organ procurement organizations to ensure legal and medical requirements are honored in the organ and tissue donation process; and update provisions of the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund.

Organ and tissue donation is a non-partisan issue that seeks to offer people a choice – the choice to donate life. When donation is possible, it is well validated that the opportunity to give life after tragic death can mitigate the grief of loved ones. The first-hand knowledge of the donor and recipient experience readily shared by our Organ Donation Advisory Committee (ODAC) members and their infusion of enthusiasm and commitment to the committee's work are a testament to the transformative power of organ and tissue donation. As you deliberate on the Donate Life PA Act, please consider that the next person added to the waiting list could be you, a family member, friend, neighbor or colleague.

I am honored to chair this committee of thoughtful, inspired and compassionate individuals. The committee appreciates your support, as well as that of the administration and the departments of Education, Health, Revenue and Transportation in helping us achieve our mission of saving and improving lives.

Sincerely,

Cheri L. Rinehart Chair



The Pennsylvania Department of Education's Organ and Tissue Donation Awareness (OTDA)

Project assists secondary students in pre-thinking the critical issues that surround organ and tissue donation so each teen can make an informed

decision and communicate his or her wishes to family members. The 2014-2015 program year marked the first year of a three-year contract with the Lancaster-Lebanon Intermediate Unit 13 (IU13) to administer the OTDA education project. Through research and collaboration, the IU13 developed the OTDA curriculum framework and classroom toolkit for use in secondary schools. IU13 staff provides information and curricular support to Pennsylvania's school districts and assists secondary educators in using OTDA materials and resources.

To ensure the broadest implementation of the OTDA curriculum framework, schools may propose projects through a competitive mini-grant program. The curriculum framework is multidisciplinary in nature and can be piloted by secondary teachers in any academic discipline. In the 2014-2015 school year, the following schools were mini-grant recipients:

Bald Eagle Area School District	\$5,000.00
Baldwin-Whitehall School District	\$5,000.00
Dallastown Area High School	\$1,500.00
Hazleton Area School District	\$3,000.00
Pine Grove Area High School	\$1,500.00
Twin Valley School District	\$4,000.00
West Side Career and Technology Center	\$3,000.00

Approximately 7,380 students received information regarding organ and tissue donation awareness through the mini-grant projects. Some of the activities completed by the mini-grant recipients included:

- School-wide awareness presentations along with outreach to neighboring schools;
- Presence at health, career and craft fairs, open houses, and parent-teacher nights;
- Public service announcements in schools throughout the month of April, Donate Life Month;
- Creation of videos, PowerPoints, posters, t-shirts, games, bulletin boards and pamphlets as
 part of the tools used to spread the word about organ and tissue donation throughout the
 schools;
- Field trips to the organ procurement organizations (OPOs), tissue banks and the Da Vinci Science Center; and
- Discussions in English classes of books dealing with organ and tissue donation topics, such as "My Sister's Keeper" and "The Nicholas Effect."

The Mini-Grant Request for Proposals (RFP) for the 2015-2016 program year was posted in March 2015. Fifteen schools applied for mini-grants, the largest number of applicants since the program's inception. Ten projects were funded and will be highlighted in the next Legislative Report.

In addition, approximately 40 school personnel attended the 2015 OTDA Institute for Educators held at the Penn Stater Conference Center in State College, Pa. on May 7 - 8, 2015. The institute included sessions on addiction and transplantation, healthy lifestyles and donation in the

multicultural community, family supports, cadaver presentations, OTDA 101 and grant writing, as well as discussions with presenters on a transplant process panel and a clinical/professional panel. Nursing continuing education credits were offered for nurse instructors and Act 48 credits were offered for secondary educators.

OTDA staff worked closely with the Center for Organ Recovery & Education (CORE), Gift of Life Donor Program (GOL), Adventures in Medicine and Science (AIMS), The Whitaker Center for Science and Arts, and other organ and tissue donation professionals to reach nearly 300 students through two OTDA student camps:

- Students attending the student camp at CORE participated in a cadaver demonstration by Distance Learning Coordinator Ray Vollmer, AIMS, Saint Louis University.
- The students who attended the Whitaker Center participated in Surgery Live and BodyWorks presentations.
- Other activities included learning about the real life stories of donors and recipients, the organ and tissue donation process, types of donors, and possible careers in the field of organ and tissue donation. Students and educators responded very positively to both camps, and plans are underway to offer three camps in 2016.



Department of Health Compliance Report

As part of licensure and complaint surveys, the Department of Health's Bureau of Facility Licensure and Certification, Division of Acute and Ambulatory Care,

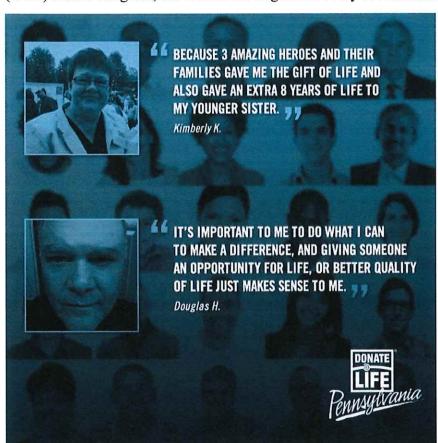
assesses Pennsylvania acute care hospitals' compliance with the provisions of the Uniform Anatomical Gift Act:

- During state fiscal year (SFY) 2014-15, 57 licensure surveys were completed. No
 hospital facility was cited for failure to comply with the federal requirements related
 to organ procurement. In 2014, hospitals were able to use accreditation for licensure,
 which decreases the number of surveys the department will do annually.
- No fines or licensure actions related to Act 102 have been imposed up to the present time.
- No facility was cited for failure to comply with the federal requirements related to organ procurement.

For transplant hospitals, in 2007, the Centers for Medicare and Medicaid Services (CMS) required that all current Medicare-approved organ transplant centers request certification to assess compliance with the federal Conditions of Participation for transplant hospitals. In May 2013, transplant survey activities were transitioned to a CMS contractor.

The **Voluntary Benefits Program** is also administered by the Department of Health. In 2014-2015, over 100 people received support through hotel reimbursement of lodging expenses associated with living donor procedures and grief counseling for family members of deceased donors.

Donate Life Pennsylvania (Donate Life PA) is a collaborative initiative between Gift of Life (GOL) Donor Program, the Center for Organ Recovery & Education (CORE) and the



departments of Health and Transportation. It is funded by residents of Pennsylvania through voluntary contributions included with driver's license renewals, vehicle registrations and state income tax filings. All contributions are used by the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund to educate Pennsylvanians, build awareness about the importance of organ and tissue donation, and increase the number of people who sign up to become donors on their driver's license, learner's permit or state identification card.

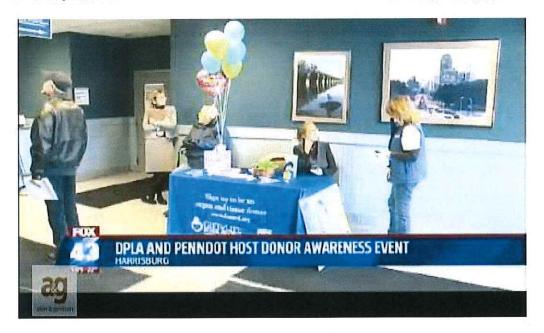
In 2014-2015, Donate Life PA put out a call for stories online – asking people to tell us why they registered to become an organ donor. Some of the most poignant stories were featured in a follow-up post reminding everyone about Donor Day on Feb. 14, 2015, with the call to action to register as a donor. Most importantly, we were able to engage with people and acknowledge the stories they have to share. We continued to find that real story posts – either sharing stories or asking people for their own experiences – were the most powerful engagement methods throughout the year. In addition, people remained intrigued by facts about donation, which corresponds to the consistently high traffic to that section of www.donatelifepa.org.

In the Resolve to Register Campaign, former Physician General Dr. Carrie DeLone urged Pennsylvanians to "Resolve to Register" as an organ and tissue donor in the 2015 New Year. Press releases and broadcast-quality video of Dr. DeLone's personal message were distributed to key markets across the state. The following messaging was used during the campaign:

- Donate Life PA makes it easier than ever by allowing current non-donors to register anytime at www.donatelifepa.org;
- It only takes 30 seconds to give the gift of life, and one organ and tissue donor can save or enhance the lives of more than 50 people;
- Unlike other resolutions that may take weeks or months to accomplish, this is one resolution that is easy and only takes 30 seconds; and
- Each day across the United States, 21 people die due to the lack of available organs for transplant, and more than 8,500 people in Pennsylvania are waiting for a life-saving organ transplant.

February 13, 2015

AUDIENCE: 15,944



National Donor Day is celebrated annually on Feb. 14. In 2015. working collaboratively with the Department of Transportation (PennDot), Donate Life PA "took over" select PennDOT locations across the state on Friday, Feb.

13. Volunteers from CORE and GOL who have been personally involved with organ and tissue donation, either as recipients themselves or members of a donor family, staffed eleven locations to answer questions about organ and tissue donation registration. As a result of press outreach, we secured more than seven broadcast clips, which totaled more than two million media impressions. We were thrilled to see coverage by multiple stations in Harrisburg and Philadelphia including CBS21, FOX43, WGAL and FOX29.

National Donate Life Month – celebrated annually in April – features an entire month of local, regional and national activities to help encourage Pennsylvanians to register as organ, eye and tissue donors and to celebrate those who have saved lives through the gift of donation. For National Donate Life Month in April 2015, we revisited the stories of recipient and donor individuals and families featured in the "30 Seconds" campaign from 2013 and reached out to journalists to share the updates. We interviewed six individuals, learning what changed since the original campaign and what they wanted to share with the public. Once the interviews were completed, we were able to craft pitches and begin sharing their stories with reporters. We secured clips on KDKA radio in Pittsburgh and a feature in the New Pittsburgh Courier. An effort like this brings awareness to the importance of organ and tissue donation by capitalizing on news coverage. Additionally, in April and May 2015, the Donate Life PA website registered 60,962 new visits and 328 new organ donor designations.

GOVERNOR ROBERT P. CASEY MEMORIAL ORGAN AND TISSUE DONATION AWARENESS TRUST FUND

July 1, 2014 - June 30, 2015

Beginning Balance		\$1,847,382
Revenue:		
Driver's license applicants		\$238,547
Vehicle registrations		\$496,368
Private donations		\$50,495
Redeposit of checks		\$0
State income tax contributions		\$15,423
Interest/investment income	-	\$3,387
Total revenue		\$804,220
Total Funds Available		\$2,651,602
Expenditures:		
Department of Health		(\$874,557)
Statewide education and information campaign	(\$779,540)	
Voluntary benefit program reimbursements	(\$16,176)	
Personnel/operating	(\$75,539)	
Advisory committee	(\$3,302)	
Department of Education		(\$206,580)
Department of Transportation		\$0_
Total expenditures.		(\$1,081,137)
Ending Balance	-	\$1,570,465

ONE ORGAN, TISSUE AND EYE DONOR CAN save up to eight lives and help improve the lives of more than 50 people:

Free two people from dialysis treatments;
Give sight to two people;
Repair injured joints or help save an arm or leg threatened by cancer or other illness; and
Help burn victims heal more quickly.

Pennsylvania Organ Procurement Organizations Update July 1, 2014 through June 30, 2015

CENTER FOR ORGAN RECOVERY & EDUCATION (CORE)

Pennsylvania Counties Served:

Allegheny, Armstrong, Beaver, Bedford, Blair, Bradford, Butler, Cambria, Cameron, Clarion, Clearfield, Crawford, Elk, Erie, Fayette, Forest, Franklin, Fulton, Greene, Huntingdon, Indiana, Jefferson, Lawrence, McKean, Mercer, Potter, Somerset, Venango, Warren, Washington and Westmoreland

Pennsylvania Population Served: 4.2 million

Pennsylvania Organ Transplant Centers Served:

Allegheny General Hospital, Children's Hospital of Pittsburgh UPMC, University of Pittsburgh Medical Center Presbyterian and Veterans Administration Pittsburgh Healthcare System

Pennsylvania Tissue Procurement Providers Within CORE's Service Area:

Center for Organ Recovery & Education (CORE)

Pennsylvania Eye Procurement Providers Within CORE's Service Area:

Center for Organ Recovery & Education (CORE) and Lions Eye Bank of Northwestern Pennsylvania

ORGAN DONATION

Total number of referrals	/,46/
Total number of potential donors	
Total number of donors recovered	
Total number of organs recovered	735
Total number of organs transplanted	533
Total number of organs provided for research	
TISSUE DONATION	
Total number of referrals	24,863
Total number of potential donors	2,985
Total number of donors recovered	
Total number of tissue grafts produced	24,650
EYE DONATION	
Total number of referrals	24,863
Total number of potential donors	
Total number of donors recovered	
Total number of eye tissue procured	
Total number of eye tissue transplanted	
Total number of eye tissue provided for research	

GIFT OF LIFE DONOR PROGRAM (GOL)

Pennsylvania Counties Served:

Adams, Berks, Bucks, Carbon, Centre, Chester, Clinton, Columbia, Cumberland, Dauphin, Delaware, Juniata, Lackawanna, Lancaster, Lebanon, Lehigh, Luzerne, Lycoming, Mifflin, Monroe, Montgomery, Montour, Northampton, Northumberland, Perry, Philadelphia, Pike, Schuylkill, Snyder, Sullivan, Susquehanna, Tioga, Union, Wayne, Wyoming and York

Pennsylvania Population Served: 7.8 million

Pennsylvania Organ Transplant Centers Served:

Albert Einstein Medical Center, Hahnemann University Hospital, Children's Hospital of Philadelphia, Geisinger Medical Center, The Hospital of the University of Pennsylvania, Harrisburg Hospital, St. Christopher's Hospital for Children, Temple University Hospital, Penn State Milton S. Hershey Medical Center, The Lankenau Hospital, Lehigh Valley Hospital, Crozer Chester Medical Center and Thomas Jefferson University Hospital

Pennsylvania Tissue Procurement Providers Within GOL's Service Area: Gift of Life Donor Program, CryoLife, Inc., LifeNet Transplant Services, Musculoskeletal Transplant Foundation and National Disease Research

Transplant Foundation and National Disease Research Interchange

Pennsylvania Eye Procurement Providers Within GOL's Service Area: Gift of Life Donor Program, Lions Eye Bank of Delaware Valley and Northeast Pennsylvania Lions Eye Bank

ORGAN DONATION

Total number of potential designation	420
Total number of donors recovered	
Total number of organs recovered	1,527
Total number of organs transplanted	1,164
Total number of organs provided for research	
TISSUE DONATION	
Total number of referrals	38,244
Total number of potential donors	5,063
Total number of donors recovered	
Total number of tissue grafts produced	
EYE DONATION	
Total number of referrals	38,244
Total number of potential donors	
Total number of donors recovered	2,225
Total number of eye tissue procured	
Total number of eye tissue transplanted	3.054
Total number of eye tissue provided for research	



From July 1, 2014 through June 30, 2015, 43,734 organ donor designations were added to driver's licenses and state identification cards.

County Ranking by Participation in Organ Donor Designation on Driver Licenses and Identification Cards

Source: Pa. Department of Transportation, July 2015

Rank	County	Total Licenses and ID Cards	Organ Donor Designation	. Дера нте %
1	Centre	94,515	53,371	56.47%
2	Chester	387,101	217,401	56.16%
3	Warren	31,316	16,968	54.18%
4	Cumberland	199,368	106,645	53.49%
5	York	352,133	186,411	52.94%
6	Montgomery	658,613	342,284	51.97%
7	Butler	152,437	78,412	51.44%
8	Wayne	44,252	22,731	51.37%
9	Susquehanna	31,696	16,271	51.33%
10	Adams	79,002	40,289	51.00%
11	Bucks	519,288	263,853	50.81%
12	Erie	209,904	106,515	50.74%
13	Cameron	4,058	2,059	50.74%
14	Bradford	48,161	24,381	50.62%
15	McKean	32,070	16,226	50.60%
16	Lancaster	403,641	204,211	50.59%
17	Montour	14,765	7,401	50.13%
18	Elk	26,225	12,984	49.51%
19	Blair	98,775	48,504	49.11%
20	Union	29,243	14,356	49.09%
21	Lackawanna	164,712	80,840	49.08%
22	Lycoming	89,729	43,767	48.78%
23	Allegheny	965,332	467,667	48.45%
24	Wyoming	23,530	11,373	48.33%
25	Dauphin	216,443	104,233	48.16%
26	Clinton	26,654	12,835	48.15%
27	Franklin	115,503	55,187	47.78%
28	Clearfield	60,811	29,024	47.73%
29	Tioga	33,074	15,746	47.61%
30	Lehigh	270,698	128,851	47.60%
31	Crawford	67,489	31,916	47.29%
32	Lebanon	109,304	51,592	47.20%
33	Northhampton	256,073	120,841	47.19%
34	Perry	37,468	17,571	46.90%

7	Transpo	ortation, July 2013	Total		
	David	Count	Licenses	Organ Donor	%
	Rank	County	and ID	Designation	70
			Cards		46.88%
	35	Venango	40,966	19,206	46.75%
	36	Mifflin	32,596	15,238	
	37	Pike	45,856	21,421	46.71%
	38	Huntingdon	33,696	15,740	46.71%
	39	Cambria	109,194	50,486	46.24%
	40	Sullivan	4,950	2,280	46.06%
	41	Beaver	134,924	61,787	45.79%
	42	Forest	4,348	1,991	45.79%
	43	Columbia	49,848	22,821	45.78%
	44	Delaware	440,320	201,294	45.72%
	45	Mercer	87,901	40,043	45.55%
	46	Washington	171,504	77,917	45.43%
	47	Potter	13,480	6,087	45.16%
	48	Westmoreland	285,620	128,865	45.12%
	49	Somerset	59,723	26,694	44.70%
	50	Berks	320,555	142,590	44.48%
	51	Jefferson	35,846	15,888	44.32%
	52	Lawrence	73,673	32,454	44.05%
	53	Snyder	29,308	12,851	43.85%
4	54	Schuylkill	113,131	49,578	43.82%
	55	Carbon	51,823	22,566	43.54%
-	56	Indiana	61,934	26,554	42.87%
	57	Northumberland	71,270	30,516	42.82%
	58	Armstrong	58,173	24,768	42.58%
	59	Juniata	17,555	7,466	42.53%
	60	Monroe	134,833	57,328	42.52%
	61	Bedford	39,901	16,965	42.52%
	62	Luzerne	250,857	105,774	42.17%
	63	Clarion	28,546	12,010	42.07%
	64	Greene	28,049	10,956	39.06%
	65	Fulton	11,895	4,642	39.02%
	66	Fayette	113,646	42,744	37.61%
	67	Philadelphia	1,098,911	338,549	30.81%
	57	TOTAL	9,908,215	4,598,785	46.41%
		IJIAD	7,700,213	1,070,700	WEST STATES